JULY 10, 2013 MINUTES
PATIENT CHOICE AND MEANINGFUL DISCLOSURE
HIE WORKGROUP OF THE GOVERNING BOARD OF THE
ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority ("Authority"), pursuant to notice duly given, held a meeting of the Patient Choice and Meaningful Disclosure Workgroup ("Workgroup") at 10 a.m. on July 10, 2013 at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

Participant Name	Participant Representation
Alan Berkelhamer	Walgreens
Alina Braica	The Association House of Chicago
Brenda Bishop	Affiliated Surgeons of Rockford
Brigid Leahy	Planned Parenthood (IL)
Charles (Chuck) Cox	MetroChicago HIE
Cheryl Jansen	Equip for Equality
Cory Verblen	Office of Health Information Technology
Crissie Anderson	Lutheran Social Services of Illinois
Crystal VanDeventer	Lincoln Land Health Information Exchange
Danny Kopelson	Office of Health Information Technology
David Carvalho	Illinois Department of Public Health
Deb Gory	Metropolitan Chicago Healthcare Council
Dia Cirillo	Office of Health Information Technology
Eric Swirsky	College of Applied Health Sciences
Glenn Susz	APP Design
Howard Lee	Wirehead Technology
Jodi Sassana	MCHC MetroChicago HIE
Joseph T. Monahan	Monahan Law Group, LLC
Katy Yee	DuPage County Health Dept.
Laura Ashpole	Popovits & Robinson
Lauren Wiseman	Central Illinois HIE
Lorie Chaiten	ACLU (IL)
Marcia Matthias	Southern Illinois Healthcare
Maria Pekar	Loyola University Health System
Marilyn Lamar	MetroChicago HIE
Mark Chudzinski	Office of Health Information Technology
Mark Heyrman	University of Chicago Law School
Mark Pellegrino	Illinois Health Information Exchange
Michelle Ward	Anderson Hospital
Mike Jennings	Walgreens

Mikki Pierce	Atrium Advisory Services Inc.
Nancy Newby	Washington County Hospital; ILHIE Authority Board
Ramon Gardenhire	AIDS Foundation of Chicago
Renee Popovits	Popovits & Robinson
Sarah Koenig	APP Design
Shira Mendelsohn	Office of Health Information Technology
Steve Lawrence	Lincoln Land Health Information Exchange
Susan S. O'Keefe	Metropolitan Chicago Healthcare Council
Susan Strange	Aetna Better Health
Theresa Walunus	Chicago Health Information Technology Regional Extension Center

Call to Order, Roll Call, and Introductions: 10 am

+ Committee Introduction: Mark Pellegrino (staff liaison) introduced himself to the patient consent and meaningful disclosure workgroup. Participants documented their names and contact information.

+ Participant introduction: Attendees in the conference room stated their names and the organizations with which they work. Participants in Springfield stated their names and the organizations with which they work via videoconference.

+ Mark Pellegrino expressed that two handouts would be made available to the workgroup: the agenda and the subgroup preferences ballot. Amendments to the workgroup minutes from June 26th were update to include a revised list of attendees and a proposed change on page five to the best practices discussion.

+ David Carvalho (committee member) introduction: [Provided his background] Carvalho worked at the Department of Public Health and was requested to serve on the ILHIE board to assist with the Patient Choice and Meaningful Disclosure Workgroup. [Description of the process] The recommendations from this committee would be recommended to the Authority.

   o Description provided by Carvalho regarding how to make the process meaningful: It is important to develop consensus with the process. Consensus is developed by the power of ideas and not by the number of bodies. Therefore, if a participant generates a good idea, he should voice it because the committee will be persuaded by a solid idea. It is beneficial to serve on work groups that you can contribute to instead of attempting to stack committees to outvote others.
   o Moving Parts: David Carvalho also mentioned the idea of moving parts. The work product of this work group will be most beneficial if it considered in a context with many moving parts that may result in

precedence with other issues that follow. Upstream, there will be sensitivity about how to balance the moving parts. Everyone should feel encouraged to voice personal concerns and interests. However, it is essential not to be too parochial because this undertaking is occurring in a larger context and recognition of this can make contributions more valuable.

- o Disclosure: David Carvalho disclosed that in addition to being a Department of Public Health employee, he volunteered as a provider on the cook county. He tries to be mindful of conflict of interest situations. So he wanted to disclosure that he plays an unpaid and non-managerial role.

Set Structure of Subgroups:

- Mark Pellegrino: [Subgroups]: Our hope is to put structure around our workgroup. Because the number of people in the endeavor may not get us to the deliverables and ends in a timely manner, it would be beneficial to branch off into smaller groups. We have attempted to put structure with subgroups around this work group.

  - o Reintroduced Agenda: Agenda provides an outline of what we thought the subgroups would look like. Subgroup 4 ("Break the Glass") discussed within the preferences document and similar to the MHDDCA is an area the ILHIE would like to approach via regulation or statutory amendment.

- David Carvalho: [Meaningful disclosure at the point of care, items 1-4]: We were anticipating that you have the principles and preferences document that have been the basis of conversation. We thought we would make sure we were in consensus about which workgroup would discuss the principles and preferences document for meaningful disclosure and the anticipated deliverables from the work group. Within the principles document are elements of patient consent policy. These are the items discussed in the meaningful disclosure point of care work group. This work group would also include notice of privacy practice, development of a general notice and forms. We would have to determine presumably how often this notice would need to be provided.

  - o [Items are 5 & 6] 5 delves into meaningful disclosure at the provider point of care, 6 delves into meaningful disclosure at the level of the HIE website.

  - o Comment: The principles document are on the work groups web page on the ILHIE website.

  - o Determine which group will discuss the information: Go through the preferences to put the items in the correct subgroup: Group 1→ 1, 2, 5, & 6, Group 3: 3d, Group 4: 4b

- [Recap of last meeting] We left off at number 1. As a workgroup we have had consensus through idem d on item 1.

  o Participant Comment: [Confusing verbiage] It is confusing when discussing consent and opt-out. Under current law, most things are subject to an opt-out and yet, we still have to deal with consent. In some places we are saying consent management policy and it is really referring to opt-out policy. We need to distinguish consent from an opt-out model. We are not assuming the statutes are yet amended. So when work is being done by the first workgroup, they would work on an opt-out policy and form, but also need a confidential sheet.

    ▪ Mark Pellegrino Comment: These groups are not mutually exclusive.

    ▪ David Carvalho Comment: We will try to get a phrase and stick to it so we don't have confusion. We have been trying to figure out if certain words are nouns or verbs.

- Participant Question/Comment: In all of these topics, one topic informs the others, so how can individual subgroups consider each issue simultaneously in different subgroups? We might need to consider the issues in succession.

  o Mark Pellegrino Comment: We can reconvene at the end of the meeting as an entire group. There are obviously other models and no model is perfect, but this model [subgroups] was recommended by the Co-chairs and the ILHIE.

  o Dave Carvalho Comment: [Accept the weakness of the model] If 50 people go line by line it would be unwieldy. Our model is not strategic, but we simply do not have the time to go line by line with 50 people. The point is valid and ultimately issues may need to be reconciled and staff should keep the other work groups informed. The model will be a little imperfect, but it will get us to a result.

- Marcia Matthias: [Item 2] Collection of patient data. Does anyone have comments about a, b, or c or need clarification about what this section means?

- Participant Comment: [regarding an earlier point about the registry] If the state of IL is going to have a database of who has consented and who has not consented, it may make constituents nervous.

- Mark Pellegrino Comment: [Reference back to language] Patient consent preferences refers to patient opt-out for this workgroup's purposes. The framework around this document is not a finished piece of work or policy, but requires a robust discussion around it.

  o Dave Carvalho Comment: Let's choose words and use them consistently.

- Marcia Matthias: Even though we are categorizing, it is helpful to refer to the whole document and refer back to consistent language.

- Participant Comment: Regarding the MPI registry, we have to be careful.

  - Mark Pellegrino Comment: I think you are reading more into the language than exists

  - Dave Carvalho: It is good to be aware of multiple ways the architecture may evolve and to make sure the language is consistent.

- Participant Question: Was the agenda ever pushed out?

  - Mark Pellegrino Comment: There should be a new invitation which attaches the agenda. The people in Springfield should have printed copies. For the people on the phone, the agenda was created and pushed out this morning.

Opt-Out Discussion:

Dave Carvalho Question: [Section 2] Regarding the collection of patient opt-out in HIE, Marcia invited comments on a, b, or c. Are there any issues you can spot that might be a good idea to flag?

- Participant Comment: With respect to item c it might be helpful to add the provider standpoint since the patient can revoke anywhere or through any provider, it might be an expectation that each time a patient comes in, there should be a query to see if a patient revoked.

  - Participant Comment: I don't think that it is practical from a clinical point of view.

- Participant Question: What is the expectation? If the patient has opted out at the HIE level, have they opted out from every provider?

  - Mark Pellegrino Comment: At this time, there is no capability to opt-out via the ILHIE Authority website so it will all take place at the point of care and will be transferred electronically to indicate whether the patient has opted out or not.

  - Dave Carvalho Comment: If there is a routine part of care to check the registry to check if the opt-out status has changed, it creates a burden. If there is not that expectation, then did the opt-out happen?

o Participant Comment: [Regional HIEs] When an opt-out happens and the HIE is notified, for the regional HIEs which is handled electronically, the patient disappears. The data is not visible to anyone. So if the patient registers, their data is not there. If the patient went query, only the EMR can be seen. Maybe we should have venders in the room because they can answer questions about how the state HIE works.

- Dave Carvalho Comment: It might be helpful to have vendor representation. However, a vender can respond with the answer but not stop the questions. Is it necessary for the provider to question every time? No, it's not because if the patient opts-out then the patients information will be masked.

- Participant Comment: But you have to be able to reverse the opt- out. A patient can change his mind later and so certain technological capabilities must be retained.

o Participant Comment: Is there a way for patients to monitor and verify that they indeed are now in an opt-out status?

o Dave Carvalho Comment: Direct patient for the management of their own consent preferences may be available at a future date. It will not be made initially available but there are thoughts about how to make that available in the future. The suggestion that answering some of these questions will be better facilitated by having vendors, RIOs, and ILHIE staff in the room is a good suggestion. We don't want to come up with preferences and policies that are platonic ideals. I think we have identified things for advancement. Any other thoughts on 2?

Registry, Federal, State, Regional Discussion

- Participant Question: [Comment on 3b] The ILHIE MPI will be the central registry? How is that going to happen if providers do not give information into the MPI?

- Mark Pellegrino: We will make a mechanism available for ensuring that patient opt-out choice is accurately and consistently applied. If a RIO is unwilling and unable to share information, then we have an obligation to recognize patient consent and if that exists with a RIO, we need to have notice of it.

- Dave Carvalho: Taking a step back, when a statute was being contemplated, my sense from the advocates was this issue

about whether someone had the right to opt-out was critical. There is an expectation that if a person opts-out, he is effectively opting out everywhere. A mechanism should be made that if there is an opt-out at the regional level then everyone at the state level should be made aware. The proposed mechanism is that ILHIE collect this-opt out information from everyone at the regional and state level.

- Participant comment: Part of the issue at the federal level is the lack of patient identifier. We are where the ONC began 9 years ago. They realized it was impossible to implement this undertaking.

  - David Carvalho Comment: I want to clarify that the federal rule does not trump state prerogatives in this matter. As a practical matter, if the feds went a different way because it was impractical, that is something that should be discusses. The question is, to be faithful to the intended legislation, what do I do? If I want my information not included anywhere in the ILHIE, what are you suggesting I do?

  - Participant Response: You opt out with the ILHIE, during the gap time it won't be a centralized database. There is a practical implementation timeline because, if suppose the regulations went into effect tomorrow, the data sharing agreement is not in place between the ILHIE and RIOs.

    o David Carvalho Response: The fact that there might be a gap in implementation does not make the gap the ideal (the gap could last forever).

  - Comment: Our constituents value that they can direct Metro Chicago to share with the ILHIE or not share.

    o Dave Carvalho: Patient says I don't want to have my information shared with ILHIE then they are opted out of ILHIE. But suppose the patient doesn't know about ILHIE and the doctor says here is the consent form, would the doctor say this opt-out is only affected in this location?

    o Participant Comment: Yes, whatever provisions are in the data sheet with MetroChicago and

ILHIE would have an impact. That's the same with every RIO you interact with. With the other aspect, Decater IL patients receive care in Decater. Both hospitals are part of Central IL healthcare and then they go to Springfield, a different HIE. That patient will need to opt out of both.

- o Dave Carvalho: Why shouldn't the patient just say I'm out and have opt-out affected everywhere?

- o Participant Comment: There are different data sharing interests. The patient has the relationship with the hospital and with each HIE and not just with the state. The relationship of the data resides with the patient and that's how it is explained to the patient. Each provider has a relationship with you.

Technology Discussion

- There are limitations to the technology but there is nothing magic behind saying to the RIOs that this patient is out and then that notifies other RIOs.

  - o Mark Pellegrino Comment: The point of this exercise is to make that happen. The technology people at the ILHIE have not said it is impossible for the state and RIO to communicate to transmit patient opt-outs. You don't have to sign a data sharing agreement.

      Participant Comment: HB1017 says, if we come together that all will follow the rules, it does not say there is a central database.

    - Mark Pellegrino Comment: That's mis-categorizing what's been said. If the RIO does not want to share the ILHIE MPI, then the ILHIE and RIO collaborate on how a patients opt-out consent will apply to all participants in the ILHIE

    - Comment: What's the point of the having a statewide HIE? If our goal is not to have a statewide authority, then what was the point of HB1017?

    - Participant Comment: We think it will be rare relative to the amount of data at Metro Chicago, that it will flow

in different regions – there will probably be more commonality because that is where the patient mass is.

- Comment: That's not how substance abuse works

o Participant Comment: Should this be discussed with the technology subcommittee?

  o Mark Chudzinski Comment: There is a workgroup looking at segmentation to allow for more granular patient choice when the technology permits it. That group is looking at only a small subset of technology.

  o Participant Comment. Regarding EHR software. Most things can be developed in modules. We can typically input what you want so long as you identify what you need in terms of opt-out. If I go to a provider and say I want to opt-in just a country, then we can make it so that everyone else is locked out.

  o Participant Comment: If you don't share your patient information but want to be in the ILHIE, how does this work? If I don't make an inquiry how do I know if a patient is opted in? Lets put together a group to discuss information, patient name and demographics, treatment, or lab reports. There is nothing wrong with just saying the patient's name and whether he has opted in. As a patient I have no idea what I am getting into.

  o Participant Comment: Metro Chicago HIE covers – we are across 9 counties covering 9 million patients and patient portal access is important to us. Beyond what we are describing you end up creating more questions because someone says I am in Dr. X, why isn't that information in there. Might say because Dr. X is not in that system. It drives so many health desk questions. We look at it and we are trying to figure out where to do that?

  o Participant Comment: Can build one software and accommodate for variations. Right now it seems like you want security for those patient healthcare records and our mission here is to share data. If we don't do that, you have 9 million patients and he has 2 million patients, then you keep building things differently and then he is over on this side and the patient who he is supposed to be taking care of is in the middle and says I want you to share my information with him. We have to say we share the information with each other because that is in the best interest of the patient and not the corporate entity. As a developer I am saying we can develop this. Where is your road map? Yours is in one and his is in another. I can make a module that is just for your hospital

and has your protocols and records. But in this ILHIE, I can say I can give you the data from here. Let the patient have some input. From what I am seeing now, it's like designing 6 pieces of software. I need just one software and can develop different module for you. It's like building a car with different engines.

- o Participant Comment: Every one of us developing an HIE has a vendor and do business nationally. If the standard is that IL is completely different, then the vendor has to design software that is different than anywhere else.

  - Participant Response: I can build interoperability.

  - Participant Comment: Interoperability is designed at the federal level. Not even ONC has been able to resolve this and they have been struggling.

  - Participant Comment: We don't like to over-promise to the patient. From the patient's interest, we can't give them something that is not technologically there. We have to be careful and mindful of the technological state. A lot is driven at the federal level.

  - Dave Carvalho comment: We bounce back and forth regarding technology and our aspirations. We can't choose things that technology can't do for 10 years (that would not be the right decision). On the other hand, accommodating for technology today and not looking to the future is also the wrong choice. So as we have these conversations to determine what the software can, can't, and will be able to do. But someone can say, I want the consent to be a categorical amount, 17 types of information. We know the technology can't do that probably for the next couple of years. It is a nice aspiration but we want to hit the sweet spot in between what is likely doable keeping in mind the end product. It may take months or half a year, not the next couple of weeks to determine what is optimal. The point about the national identifier is not an ILHIE or RIO problem it is a hospital-hospital problem. We have the problem that Joe Smith who comes in is which Joe Smith record? Sadly, we are creating duplicate medical records with numbers that are unsatisfactory. It is not a roadblock to sharing at the RIO-ILHIE level, not a roadblock at the hospital, but it is a challenge.

- o [Agenda] Participant Comment: Did we assign anything other than 3d to a subgroup? Is it worth assigning this issue to the technology group?

o Dave Carvalho comment: It is probably better for the workgroup to come up with what we would like the technology group to do and decide the timeline: technology for tomorrow, 6 months from now, etc. However, we should not have technologists decide what is the right policy for patient consent.

o Participant Comment: How will this undertaking be enforceable if there are limitations to the technology? In developing the administrative rules, how will our recommendations be enforceable if the technology cannot support it?

> o Dave Carvalho Comment: We would not create policies that technology cannot accommodate for. We just don't want to start with the premise, here is what the technology can do, and this is going to inform our policy choice.

> o Dave Carvalho Recap: Over the course of several months this group will develop recommendations. This committee will process these recommendations. The Authority commences the rule making, which is a 6-9 month rule making process as well. Realistically, there won't be a rule in place for 9 months or a year. Over that time frame, the discussion will be an evolving one. My suggestion is that the ending point of the policy choices shouldn't be limited by the technology of today but should be informed where the technology is going into the near future. It would be imprudent on behalf of this committee to adopt a rule that can't be implemented, but we don't want to be limited by today's technology.

> o Mark Pellegrino Comment: One voice says the technology is very doable and another saying it can't be done. ILHIE will collaborate with the RIOs to evaluate and identify a mechanism to ensure that recommendations are accurately applied across all RIOs.

>> ▪ Participant Comment: We need to be objective in these groups and have representation from different perspectives and to strongly consider the patient perspective.

>> ▪ Participant Comment: We are discussing two things: What ILHIE itself is going to choose and what ILHIE expects the other HIEs in the state to do. We want to execute an agreement, but need to identify our risk assessment when we decide if we want to share data. We are trying to highlight these issues and solve them.

>>> • Dave Carvalho: I think you are accurate in that we are having a conversation about policy informed by technology, but I don't want it to go into a business

plan. My experience with my own IT department (IT ultimately takes direction from the agency) is that if you want something done, then you tell your technologist to do it. We don't want to start from what the vender can currently do because that would essentially leave everyone in the room without a vendor or RIO wondering what they are doing here.

- o Participant Comment: ILHIE's business plan talks about the providers directly connected to the ILHIE and those connected by the RIO.

- o Participant Comment: Most people want to focus on, if I am a patient and want to opt out, how do I opt-out?

- o Participant Comment: What if the patient only wants to have their records stay local and not share it with the state?

    - o Participant Comment: In Central IL, patients can give their records to some hospitals and not others.

    - o Participant Comment: I want to make the point of patient choice and making it easy for patient opt-out. Are you serving the patient's best interested when she is distracted by her screaming kids? Meaningful disclosure has to be deciding where meaningful disclosure happens. For that reason we decided it wouldn't be at the registration desk. If you aren't feeling well you might not be at a point to make the correct choice. Some of the nuances and how a patient makes that decision should be handled when they are ready to hear and they understand from someone who is experienced to explain the meaningful disclosure. You take that burden off the providers. If the register gets 15 questions, you are interfering with the workflow.

        - ▪ Dave Carvalho: It seems like there is a suggestion that this might need a group of its own?

Subgroup Discussions, Dividing Questions and Additional Subgroups:

- ➕ Participant Comment: I think opt-out and meaningful disclosure permeates all work groups. The issue of all of the opt-outs are rolled into one registry. Where do 3 a, b, and c get assigned?

    - o Mark Pellegrino Comment: In authoring this document and getting input from my peers, if an RIO elects not to send information to a master index, then → If not B then C. People are getting hung up on B because a RIO may not want to join a central registry. The point of C

is that technology people have advised us that coming up with a mechanism is not an impractical or impossible.

- ▪ Participant Comment: It works in 1. We have to be mindful when creating our work product not to raise unrealistic expectations.

- ▪ Mark Chudzinski Comment: There is currently a discussion planned, a meeting of the Regional HIE Workgroup to discuss with ILHIE's CTO three technology related questions. 1 --- MPI, 2--- interoperability, and 3-- connectivity. That is anticipated for July 29/30. That will be focused on a technology conversation and is open to the public and people interested in the policy side might want to be in the RIO Workgroup meeting. There will be minutes and it will be public and we will try to make it available as widely as possible.

- o Dave Carvalho Comment: If I can make a suggestion, having the meeting open and having the minutes available is helpful but having someone there as part of the meetings would be better. Maybe if we can send out the posting to everyone. The notices are on the ILHIE website. Did your question get addressed?

  - ▪ Participant Comment: There are some suggestions that a, b, and c go into the first subgroup and another suggestion that b and c get carved out.

  - ▪ Participant Comment: 3a goes well with first work group and 3 b, and 3c all go with work group 1.

  - ▪ Dave Carvalho Comment: Topic 4 describes data filtered by opt-out . 4b goes in group 3. Is 4 a assigned anywhere? It becomes part of the meaningful disclosure at the point of care. 4 will put in group 1.

- o Participant comment: I have comments on b. A provider does not have to accept an amendment to a medical record under HIPAA. If I have psych records or genetic or HIV/AIDS, I simply have those rights. It might lead to the conclusion. If the providers can't ensure that the record can be segmented then the patient will opt-out completely. This may be too strong. The provider is going to require those patients to opt-out of the entire ILHIE? It might not be where you want to be from a patient perspective? It might be beneficial to segment and limit the provider from sending that information. To require the patient to completely opt-out seems harsh.

- Mark Pellegrino Comment: There are many opt-out states that have that language. Whoever has the privilege of dealing with 4b can talk about that more.

- Dave Carvalho Comment: That can be part of the disclosure to the patient. Because I have an EHR that can't deal with the information, the provider does not have to share it and that needs to be disclosed to the patient that your information won't be going because we simply can't do it.

- Participant Comment: Regarding b, we may agree to a restriction that does not involve specially protected information so that might involve another bucket of information. Particular information might not be special under IL law.

- Participant Question: Regarding 4b, is that the specially protected subgroup that address those questions? There are some issues under the federal confidentiality regulations that we might want to share some guidance on regarding the opt-out and break the glass suggestions.

- Mark Pellegrino Comment: Certainly an option to combine the 2, the break the glass concerns itself in an emergency context. It would probably be a smaller subgroup and more academic. The other would be broader and more robust. I am amendable to merge those groups if there is a desire.

- Mark Chudzinski: As of September 23rd there will be another bucket about out of pocket requests.

- Dave Carvalho Comment: 5 goes into group 1 since it has the same title. Do we have any observations to make at this juncture or reserve it for the actual workgroup? It might be most efficient to defer to the group to discuss it.

Summary/ Next Steps

- We accomplished our goal of assigning everything and identifying issues of global concern. At this stage we can collect peoples subgroup preferences. It is not written in stone. You can email Mark Pellegrino with preferences. July 24th is the next meeting. We will try to assign everyone to subgroups.

  o Mark Pellegrino Comment: We have proposed the next meeting for July 24th. We will have a short introduction for the entire group. Then subgroups will break-out for the first time and we will convene back

together and discuss our next steps. Someone would take a leadership role and will decide how to meet and complete the work. I think it is best to meet as a large group every 2 weeks. We will reconvene this group on July 24th. We will have the same telephone and video capabilities. After we collect preferences from the people on the telephone and in this room, we will let everyone know their group assignment so when we meet on July 24th, everyone will know what group they are assigned to.

- o Dave Carvalho Comment: I would encourage anyone who wants to meaningfully participate in the July 24th meeting to be here in person.

- We will reconvene on **July 24th from 10–12 pm**.